



Consumer Involvement in Rehabilitation

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Dr. Thursz, who is dean of the School of Social Work at the University of Maryland, Baltimore, wrote the monograph "Consumer Involvement in Rehabilitation" for the NCCRDD conference. He characterizes consumer involvement as "an idea that runs counter to the traditional view of noblesse oblige and the modern thrust of professionalism." But this new view, he says, "ought to be welcomed by those who have the vision of the gains to be made" through involvement of disabled and disadvantaged people in the programs which affect their lives.

The monograph deals in some detail with two types of consumer participation—*independent groups operating outside the system and groups or individual consumers participating from within the system.* The following excerpts are from the discussion of the second of these two ways of involving consumers. The section is called "Engaging the System."

" . . . I am sorry. We do not give information on the telephone."

"The form must be filled out in triplicate, and notarized . . ."

"The policy of our agency requires that the person in need present himself at our downtown office."

"We close at 4:30 p.m. Come back next Monday . . ."

These are typical bureaucratic responses to a call for help. The size of our service systems and the layers of structure create formidable obstacles to those for whom these various agencies have been created. The persistent complaint is that the process of getting service is interminable, highly impersonal, and inflexible. "It's as if they really don't care," said one clinic patient. A maid, she had spent the entire day in a reception room waiting for a regular diabetic test that takes only a few minutes. In the process, she had lost a day's wages.

One of the major reasons for involving consumers within our service systems is for them to influence the way our programs of rehabilitation are organized. Their insights can guide us in evaluating and increasing the effectiveness of our methods.

In the rehabilitation field, service systems vary greatly as to size, sponsorship, function, and structure. No plan developed for one particular institution is automatically applicable to all. There are no panaceas and few well-tested principles. We still face the dilemmas and knotty issues that emerged a few years ago when some blue-ribbon advisory and policy-making boards were transformed by the first appearance of consumer representatives.

There are four major areas of function which we will review in order to indicate some ways by which the consumers of service can be involved. They are:

1. Planning and policy determination.
2. Provision of service as employees of the service system.
3. Funding of specific programs to be directed and staffed by consumers.
4. Establishing an advocacy program within the service system.

Planning and Policy Determination. Under the impetus of the "maximum feasible participation" concept enunciated by the legislation for the Office of Economic Opportunity, a large number of institutions and other types of service systems began to appraise critically their planning and policy boards. Many thought that they had dealt with the problem of consumer representation by establishing advisory boards, either composed entirely of consumers or including a significant number. Ten years ago, this might have been perceived as a constructive step. Today, the creation of advisory bodies is seen as a delaying tactic by those who are insisting on consumer representation as a matter of right.

Advisory boards—by definition—have no power. The decision-making is left to another body of either lay or professional personnel. This is not "a piece of the action." It is at best a belated recognition of the exclusion of those most affected by the activities of the service system.

This may seem a harsh dismissal of a progressive idea. The fact is that the disadvantaged and the disabled must be granted some degree of power within the service system. Without the right to exercise a vote on all the matters that normally are brought to a board of directors, the handicapped population

served by the institution will still feel excluded and impotent.

The experience of agencies and institutions that have granted voting power to representatives of the clientele being served has, thus far, demonstrated that their presence has not destroyed the institution, nor has it limited the effectiveness of the services given. On the contrary, in many instances, the staff members and consultants have described the mutual respect and understanding that developed with the increasing candor and confidence of the total group.

The process involves destroying myths that plague not only the staff, but the client group as well. The communication problem—though not solved by any means—is lessened as the consumers' grapevine system is used to correct distortions and pass on accurate information. Distrust is reduced and the complexity of issues is brought to the awareness of the representatives of the clients who, often for the first time, realize that some solutions bring with them newer and perhaps equally difficult problems.

Community action agencies and the newer Model Cities boards have attempted to cope with at least two problems that the disadvantaged face when selected to serve on policy and planning bodies.

The first is the question of reimbursement for the expenses involved in attending meetings. This has ranged from the payment of transportation costs to baby sitting services and dinners, and, in some instances, the provision of stipends. Initially, the payment of such fees may seem to violate the concept of voluntarism which serves as the basis for the participation of most board members. It may also suggest a further cooptation of the representatives, who may be seen as benefiting materially from their participation. Yet, with persons whose income is extremely limited, the cost of involvement is a serious obstacle to "engaging the system."

It seems that, at the very least, the actual expense of attending meetings ought to be reimbursed by the service system. This should cover all such costs, including the provision of care for children at home. The payment of a stipend may increase the competition for the posts involved and result in the possibility of better representation.

The second problem is that of technical assistance. Planning and policy determination require the amassing of a wealth of knowledge, the careful assessment of facts, and the analysis of options. If the consumer representatives are to play a significant role, they must be able to fathom the meaning of agenda items and the various proposals submitted

"COALITION OF CONCERN"

by the staff or others. It may not be enough for the executive director to patiently explain the issues.

To be effective, the consumer representatives may need to have available to them independent technical advisors whom they trust and who will assist them in examining the issues at stake and the alternative avenues for coping with them. Arrangements can be made by the service system to employ such personnel as consultants—or the representatives may be allowed to select their own consultants.

This may appear cumbersome and complicated to the person for whom even the concept of voting consumer representatives is somewhat strange. Without such help, however, the representatives may be forced to be passive observers or "rubber stamps."

There are other techniques for giving a significant role to clients within a service system. For example, a consumer board may be established which must regularly review all policy decisions for the institution or agency. In some instances where such groups exist, they have been given veto power in certain policy areas. We can expect to have many additional models of citizen involvement in planning and policy boards from experiments now being conducted by the two new major social programs established in the past 5 years: the community action agencies and the model cities programs.

Provision of Service as Employees of the Service System. The literature dealing with the employment of poor persons within social service organizations has mushroomed during the past few years. The concept of "new careers" is generally known and there have been numerous pioneer efforts to redefine tasks in such a way that various levels of activities are identified for persons who lack professional training. . . .

If we can redefine jobs and identify the skills needed for various levels of tasks to be performed, there ought to be opportunities for our clients to become gainfully employed within our service systems.

But we can go much further. We can create jobs that never existed before and make use of the unique

skills and wisdoms of the handicapped persons with whom we work. In some instances, it will require us to recognize new roles that they can perform, precisely because they are members of a disadvantaged or disabled group.

In other instances, handicapped persons can be trained for traditional tasks to be performed in new settings. Such is the case, for example, with mothers who are being trained to provide day care in their own homes for the children of neighbors who are participating in work training.

The Federal Government has met with significant success in providing employment for mentally retarded persons under a special hiring authority established by the Civil Service Commission. In existence since 1963, this program has placed more than 5,000 mentally retarded persons in over 100 different jobs in 40 Federal agencies throughout our Nation. The success of this program, operated with the advice of the Rehabilitation Services Administration and the State vocational rehabilitation agencies, indicates that jobs can be developed for the disabled as well as for the disadvantaged.

The one caution we would add is that the employment program should be related to an educational one. Whether we like it or not, educational institutions provide individuals with "passports" that permit mobility vertically and horizontally. No "new career" program can be deemed as valid unless it gives each participant an opportunity to climb to another level on the educational ladder. This applies as much to the person in need of a high school degree as it does to the holder of a B.A. degree.

Funding of Specific Programs To Be Directed and Staffed by Consumers. The neighborhood corporation represents another important idea for consumer involvement and consumer control. It is a logical extension of the concern we have expressed for self-help and the dignity that comes from autonomy. Rehabilitation systems may be able to adapt the same concept to their work. Are there certain activities which can best be carried out by present or former consumers? Can these activities be isolated

from the rest of the program so that they can be performed independently? For example, case finding may be an important task associated with the initial phase of a rehabilitation effort. In another situation, the operation of a communal day care center may represent the first tangible assignment that can be turned over, through a subcontract, to a consumer group already existing or formed for that purpose.

We cannot underestimate the therapeutic value to a disabled or disadvantaged group of being able to operate a program—no matter how limited in scope—with total responsibility for all its aspects. Here again, technical assistance may be needed and there should be some flexibility to permit the group to make its mistakes.

In recent months, it has been suggested that poor persons can be used to provide technical assistance and support as members of consulting teams organized to assist in the development of new programs. They would not substitute for the use of competent professional personnel, but would add to the strength of the consulting or advisory team by sharing their unique perceptions and engaging other poor persons in more open dialog than would exist between professionals and poor people.

As with all other aspects, this type of citizen involvement carries with it certain risks. The desire to involve has to be placed in the context of a concern for high standards of service, careful and legitimate use of public funds, and objective evaluation. Contracts need to be drawn with care. The responsibilities of the subcontracting group must be crystal clear. Where problems have occurred, they have been largely due to confusion and a lack of legal sophistication on the part of the consumer group. Difficult as it may seem, this idea may have great value to the disabled and disadvantaged, as well as to our service systems.

Establishing an Advocacy Program Within the Service System. During the past few years, the appeals lodged by welfare recipients, dissatisfied at the decisions made by welfare workers, have risen at a very rapid rate. The reasons for this increase are not difficult to find. A few years ago, most welfare recipients did not know that there was an appeal procedure. Those who did were often unaware of the specifics, feared retaliation, or did not have the skills to collect the sort of evidence they would need. Now, the various organizations that have focused their attention on welfare are eager to inform wel-

fare clients of their rights and to offer consultation and legal advice if needed.

To many workers in the service system, such appeals are annoying. They waste time and create much additional paper work. In addition, an appeal seems to reflect on their competence and their ability to interpret the regulations correctly. Though the workers may agree as to the legitimacy of appeals, many find the entire process troublesome.

The reaction of welfare workers to appeals is not at all unique. Similar reactions can be found in any and every system—including the university, the Army, hospital, and the clinic. In brief, it is found in every human organization. Still, the individual needs protection and that need has never been greater than now. Confronted by a huge bureaucracy, he feels unequal to the task of protecting his rights or stating his case. He is alone—unfamiliar with the ways the system operates and the bases for the determinations of his worker. The worker seems to him to be both his adversary and judge. His perception may be distorted—but from his perspective, such distortions are understandable.

Faced with similar problems, the United States Army established a specific position—that of the inspector general. The I.G. is not part of the chain of command. He may be seen by anyone who feels he has a legitimate complaint. The I.G. is given unusual sanctions to move in and out of various parts of the army bureaucracy in order to ferret out the truth.

In Sweden, the ombudsman serves a similar function to “keep the system honest.” Established in 1809, the ombudsman is responsible to the legislature. His function is to investigate citizens’ complaints against public agencies. He is a public investigator and grievance commissioner combined, with power to investigate administrative agencies, examine their records, and call witnesses. This system has spread to other Scandinavian countries, to New Zealand, and to West Germany.

Traditionally in this country, however, the individual or group that wished to challenge a ruling on the part of an institution or agency could do so by following certain prescribed steps—but with little help from the system itself. The challengers would invariably have to turn to some outside agency or private advocate for assistance.

The disabled and disadvantaged are rarely in a position to turn to other systems for help, or to engage the services of a lawyer. If their rights are to be protected and the “system” kept honest, some new devices for this purpose must be created.

Consumer involvement as a principle is offered as an antidote to the problems of huge bureaucracies. . . . In essence, there must be some shift in power between the "caretakers" of the system and the users of the system—if that system is to be more responsive to the needs of its customers and to its own mission.

Responsiveness [to consumer demands and concerns] is as realistic a goal for social services and rehabilitation agencies as it is for Woolworth's and Macy's. A quick look at the annual budgets of these public agencies will demonstrate that they are big business, too.

A key factor influencing the development of consumer participation in many service systems is the massive evidence that there is a relationship between involvement and the achievement of therapeutic goals. The principal contention is that shared responsibility for decision-making and for the actual treatment enhances the potential movement by the client. Milieu therapy, patient government, ward advisory boards are all techniques based on this major idea.

Much of the present efforts to involve consumers is designed to convince the consumers that the programs worked out for them are really just what they need. They are not based on a willingness to share power, or even to listen carefully.

Part of the rehabilitative process—as crucial as any other part of the treatment methodology—is consumer involvement. The settings

may require differing approaches. In some, the boundaries may be narrower than in others. In all situations, however, the individual person must be helped to maintain and develop a sense of self-worth through the opportunity to participate in influencing his own life and his environment. Citizen participation is probably the most effective tool to counteract the tendency to encourage a sense of helplessness and dependency on the part of the clients of rehabilitation agencies.

With effective citizen participation come a series of secondary gains to the individual persons involved and to the service system. For the individual, participation often means a new camaraderie and friendships to replace those lost as a result of the handicap or those that were never there. In addition, there is the subtle but important message that he is not alone in his struggle to overcome his fate. The shame and disgrace often felt by the disadvantaged individual is slowly replaced by a new and stronger identity that enables him to speak with candor and force to those that he previously feared.

For the service system, it provides an opportunity for new insights to guide interventions and treatment strategies. And, if the consumer involvement plan is conceived with sufficient creativity and imagination, it may provide the system with a new cadre of workers to join the professionals in trying to cope with the causes and effects of the handicapping condition.

—from other sections of Dr. Thursz's paper on consumer involvement in rehabilitation.

The basic premise which has to be established at the onset is that the service system is obligated to establish, sanction, and tolerate a set of well-defined procedures by which appeals can be made and grievances heard.

The institution or agency staff will need careful training in recognizing the legitimacy of such procedures, assisting the individual or group to follow the necessary steps and withholding verbal or non-verbal disapproval of the use of this process.

Having established the premise, there seem to be two routes that can be followed in creating a program to provide consumers with advocacy services.

The first is to provide within each service system an office of advocacy, manned by a member of the staff who has both special responsibility and authority. This individual would be given the power to act within the system to make certain that his client receives the full benefit of the program of the agency. He would function as a sort of institutional public defender and be available to all who wished to "fight the system." He would have a small staff of present or former consumers to assist him.

The second alternative is to accept and encourage the role taken by some independent consumer groups

as the advocates of specific clients in their disputes with the service systems. The National Welfare Rights Organization, for instance, has urged its chapters to assume such a role. In Philadelphia, the welfare rights organization has been granted the private use of an office in each of the branches of the Department of Social Services. In Baltimore, a group of welfare mothers insisted that they be provided with a copy of the manual for welfare and a telephone at a desk to be used by the welfare rights representative and advocate, within the Department of Social Services.

The major drawback to the second alternative is the need for financing. Advocacy is an expensive process, especially when dealing with individual grievances. Perhaps such advocacy structures can be funded through a subcontract to a consumer group or some other nonprofit group or corporation.

There is also a good deal of merit to the establishment of an ombudsman-type position within the service system. The latter type of advocate might be granted a great deal more power to investigate and influence decision-making than the former, though we would need to overcome the usual distrust of a public official.

Amen, Brother!

"The consumer is all things to all people." That is the central theme of a one-act drama, *The Amen Corner of Consumer Involvement*, which was part of the conference program. That is, we all may amen the rights of the consumer, but we very often have definite and usually narrow views as to just whom we mean by consumer.

This thesis is expounded in the 15-minute, two-scene play which finds its characters (a Congressman, a lady lobbyist, a bureaucrat, and an organist) amending the preacher's theme of a consumer's right to participate in decisions affecting his life (scene one) and revealing to the preacher outside the church (scene two) that each had a different idea about whom he was amending.

The denouement, however, is provided in the seed of doubt that is planted in each character's

appraisal of his own point of view. While they leave the church much the same as they had entered, there is hope, perhaps, that a revelation may come. But, as in reality, that revelation is somewhere out there, in the future.

The final bit of irony is provided by the one line spoken by the organist, who could represent "the uninvolved people." The preacher, in confusion, asks himself "Just who did we amen?" She answers: "I don't know, brother, I only play the notes."

The play was produced by the Back Alley Theater of Washington, D.C. The author, Dan O'Connor, is radio and TV officer for SRS's Office of Public Affairs. The script is available from the author, Dan O'Connor, Office of Public Affairs, Room 5121, HEW Bldg. (S), 330 C St. SW., Washington, D.C. 20201.

